



Measuring disability among U.S. adolescents and young adults: A survey measurement experiment

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ABSTRACT

Objective: Disability is identified in surveys using various question sets, with little understanding of reliability across these measures, nor how these estimates may vary across age groups, including adolescents and young adults (AYA). The purpose of this study was to assess AYA prevalence of disability using two disability question sets and reliability of these measures.

Methods: AYA participants in the Policy and Communication Evaluation (PACE) Vermont Study completed a single-item disability question used in the National Survey on Health and Disability (NSHD) and Urban Institute's Health Reform Monitoring Survey (HRMS) and a six-item set on functioning (Washington Group-Short Set, WG-SS) from the National Health Interview Survey (NHIS) and National Survey on Drug Use and Health (NSDUH) in 2021. Prevalence was estimated for any disability and each disability domain in adolescents (ages 12–17) and young adults (ages 18–25) and compared with U.S. national estimates in NHIS and NSDUH.

Results: Using the WG-SS, the prevalence of any disability was 17.0 % in PACE Vermont adolescents and 22.0 % in young adults, consistent with the national prevalence of adolescents in NSDUH (17.9 %) but higher than estimates of young adults in NHIS (3.9 %) and NSDUH (12.9 %). The single-item question provided lower estimates of disability (adolescents: 6.9 %; young adults: 18.5 %) than the WG-SS, with low positive agreement between measures.

Discussion: The prevalence of disability in AYAs varies depending on measures used. To improve disability surveillance, it may be necessary to validate new disability questions, including among AYAs, to capture a broader range of disability domains.

1. Introduction

Public health surveillance is critical to identify population-level disparities, monitor health progress, and allocate resources appropriately (Groseclose and Buckeridge, 2017). In 2011, the Affordable Care Act in the United States mandated that federally funded population-level health surveys include disability as a demographic variable to be collected in public health surveillance (Dorsey et al., 2014; Burwell, 2014; US Department of Health and Human Services, 2011). Including disability as a demographic and not a health outcome allows for the

identification of health disparities among this population and improved knowledge of intervention effectiveness (Krahn et al., 2015). Indeed, the recognition of disability as a demographic descriptor and subsequent research on health outcomes among people with disabilities has led to the recent designation of people with disabilities as a population with health disparities by the National Institutes of Health of the United States in the fall of 2023 (National Institutes of Health, 2023). However, disability is a complex concept and there is no universal definition of disability; therefore, estimates related to the number of people with disabilities and their health outcomes will vary depending on how

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disability is defined and what mechanism is used to collect disability data (Andresen et al., 2021; Miller et al., 2011). Disability is generally defined through various models (e.g., medical, social) (Palmer and Harley, 2012). The medical model defines disability as a consequence of trauma, disease, or a health condition that causes functioning limitations while the social model of disability defines disability with respect to the interaction between a person's health condition, environment, and personal factors that influence social participation and functioning (Palmer and Harley, 2012; World Health Organization, 2001). The World Health Organization developed the International Classification of Functioning, Disability, and Health (ICF), which combined the previous models to define disability in relation to the following three dimensions: impairment, activity limitation, and participation restrictions (Palmer and Harley, 2012).

In much population-level survey research in the United States, disability is identified through participants endorsing questions related to self-reported difficulty in various functioning domains (e.g., cognition, mobility, hearing, vision). The minimum standard for disability questions in U.S. national health surveys is the American Community Survey (ACS) 6-item set of disability questions (US Department of Health and Human Services, 2011; Brault, 2009; US Census Bureau, 2021). This disability question set is used by many surveys, including the U.S. Census Bureau for the American Community Survey, the U.S. Department of Education in the National Postsecondary Student Aid Study, and the U.S. Department of Health and Human Services in the Behavioral Risk Factor Surveillance System (BRFSS) (Centers for Disease Control and Prevention, 2024). However, these questions have a number of limitations, such as inconsistent endorsing of the questions over time and under-counting of psychiatric disabilities and developmental disabilities among high schoolers (Hall et al., 2022). As the ACS questions are a minimum standard, some surveys have used alternative questions, including the Washington Group-Short Set (WG-SS), which was designed to be a census question set on disability that would be internationally comparable (Miller et al., 2011). Some health surveys in the United States have recently switched from the ACS to the WG-SS, such as the National Health Interview Survey (NHIS) in 2019 (National Center for Health Statistics, 2020) and the National Survey on Drug Use and Health (NSDUH) in 2021 (Center for Behavioral Health Statistics and Quality, 2022). Finally, a single-item self-identifying disability question is used as a screener for a national survey assessing the health of people with disabilities and was included in the Urban Institute's Health Reform Monitoring Survey (HRMS) from 2014–2022 (University of Kansas Institute for Health and Disability Policy Studies, 2023; Urban Institute, 2023). Of note, this single-item question provides an option for mental illness/psychiatric condition while the ACS and WG-SS do not have specific questions related to mental health, although an extended version of the Washington Group question set is available that queries about anxiety and depression (Loeb and Altman, 2016).

Although the ACS and WG-SS question sets are similar, differences exist in wording and response options. The ACS queries about the following functional domains: cognitive, hearing, independent living, mobility, self-care, and vision and requires a dichotomous yes/no response. The WG-SS asks about communication rather than independent living and therefore asks about the following domains: cognitive, communication, hearing, mobility, self-care, and vision. The WG-SS also allows for the assessment of a range of functioning by having the following response options: "no difficulty," "some difficulty," "a lot of difficulty," or "cannot do at all." Meanwhile, the HRMS's single-item disability question asks if a respondent has a disability or requires assistive technology and, if endorsed, allows for the respondent to select a disability category (e.g., intellectual/cognitive, sensory). Due to these differences, disability estimates vary by question set. Previous research comparing the ACS and WG-SS in adults indicated the ACS estimates approximately twice the percentage of adults with disabilities than the WG-SS (Weeks et al., 2021; Lauer et al., 2019; Landes et al., 2023). Additionally, the two question sets do not always classify the same

respondents as having a disability, with approximately 13 % of respondents endorsing either the ACS or WG-SS, but not both (Weeks et al., 2021). When comparing the question sets to the single-item disability question, 20 % of respondents who endorse the single-item question do not endorse the ACS and 43 % of respondents who endorse the single-item question do not endorse the WG-SS (Hall et al., 2022). In young people, previous national estimates of disability range from approximately 5 % to 14 % of children 0–17 (Hagerman and Houtrow, 2021) to 6 % of adolescents and young adults (AYAs) aged 14–24 (Cheng and Shaewitz, 2020) to 25 % of adolescents aged 12–17 (Trends in prevalence of disabilities among youth, 2022); yet little is known on whether and the extent to which this variability results from true underlying differences in the populations and/or differences in measurement.

Given the importance of identifying disability and health outcomes among this population to ensure appropriate resource allocation and reduce health inequities and the limited research on how AYAs respond to various disabilities questions, further research on how AYA respond to various disability questions is needed. The goal of this study was to assess the prevalence of disability in AYA using two different disability questions and estimate the reliability of these measures. Further, the generalizability of findings was assessed by comparing the prevalence of disability in Vermont AYA to national datasets that are similarly used to assess drug use and health outcomes and ask the same disability measures.

2. Methods

2.1. Data sources

Data were from the 2021 Policy and Communication Evaluation (PACE) Vermont Study, an online cohort study of AYA Vermonters aged 12–25 recruited through web- and community-based methods and participant referrals that assesses substance use beliefs and behaviors associated with statewide prevention efforts (Villanti et al., 2020). Disability items were assessed in Wave 8 conducted in September 2021 with 509 respondents (145 adolescents, 364 young adults). Comparison with national prevalence estimates was conducted using the 2021 NHIS, 2021 NSDUH, and 2020 National Survey on Health and Disability (NSHD). NHIS and NSDUH are annual household surveys providing information on the health status of people in the U.S (National Center for Health Statistics, 2020; Center for Behavioral Health Statistics and Quality, 2022). The NHIS is conducted with those aged 18+, and analyses for this study included those aged 18–25 (n = 2,218); the NSDUH is conducted with those aged 12+ and analyses for this study included respondents aged 12–25 years old (n = 24,722). The NSHD is a national online survey for people with self-identified disabilities that provides information on the health of adults aged 18+ with disabilities (University of Kansas Institute for Health and Disability Policy Studies, 2022) and analyses for this study included those 18–25 (n = 205). Research related to the PACE Vermont Study was approved by the University of Vermont's Institutional Review Board (STUDY00000810); the secondary analysis of NSDUH and NHIS data was determined to not be human subjects research by the University of Vermont Institutional Review Board; survey and study procedures for the NSHD were approved by the University of Kansas Institutional Review Board.

2.2. Measures

2.2.1. Disability

Disability was assessed using the WG-SS (PACE, NHIS, NSDUH, NSHD) (Miller et al., 2011); and a single-item disability question (PACE, NSHD), with question details provided in Supplemental materials (Table S1). Questions on the WG-SS were not mutually exclusive; respondents could report difficulty in more than one functioning domain. Respondents who answered either "a lot of difficulty" or "cannot do at

all” to one of the six WG-SS questions were categorized as living with any disability (Washington Group on Disability Statistics, 2020). Respondents who answered “yes” to the single-item question about disability were then asked a follow-up question about what one category described their main disability or health condition. In the NSHD, the single-item disability question was asked before the WG-SS, while in PACE the single-item question was asked after the WG-SS.

2.2.2. Mental health

Mental health measures in the PACE Vermont Study assessed depression and anxiety symptoms using the Patient Health Questionnaire-2 (PHQ-2) and Generalized Anxiety Disorder 2-item (GAD-2) screeners (Kroenke et al., 2003; Plummer et al., 2016). The sum of the two questions provides a score for the set, and those who scored 3 or above were categorized as “yes” while those who scored less than three were categorized as “no” (Kroenke et al., 2003; Plummer et al., 2016). The mental health measure from NSDUH was a derived variable on past-year major depressive episode (yes/no). Depression measures from NHIS were coded from the following two questions: “How often do you feel depressed?” and “Thinking about the last time you felt depressed, how depressed did you feel?” Response options were: “Would you say daily, weekly, monthly, a few times a year, or never.” And “Would you say a little, a lot, or somewhere in between?” Anxiety questions from NHIS were “How often do you feel worried, nervous or anxious?” and “Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?” Those who reported *daily* and *a lot* or *daily* and *somewhere in between a little and a lot* or *weekly* and *a lot* were coded as regularly having feelings of anxiety or depression. Question details are provided in [Supplemental materials \(Table S2\)](#).

2.2.3. Sociodemographic variables

Sociodemographic variables included in all surveys were: sex (male, female), sexual orientation (heterosexual or straight, other), and race/ethnicity (Hispanic, Non-Hispanic (NH) White, NH Black, Other). Sociodemographic variables in NSDUH and NHIS included education (less than high school, high school diploma/GED, some college/associate degree, bachelor’s degree or more), annual household income (<\$20,000, \$20,000–\$49,000, \$50,000–\$74,999, ≥\$75,000) and any health insurance (yes/no). No sociodemographic variables were assessed in NSHD as all respondents in this survey reported living with a disability.

2.3. Data analysis

All analyses were completed using Stata/Standard edition version 17 (StataCorp LP, College Station, TX). Survey weights accounted for complex survey designs and a Taylor series linearization methods provided variance estimation. PACE data were weighted to be representative of youth and young adults in Vermont. Missing, “refused,” and “I don’t know” responses were removed using list-wise deletion. Missing data ranged for each survey (PACE: range, 0.2 %–4.1 %; NHIS: range, 0.05 %–5.9 %; NSDUH: range, 0 %–5.2 %; NSHD: 0 %–1.5 %). Descriptive statistics were run for sociodemographic variables using 2021 PACE Vermont, NHIS, and NSDUH data. Prevalence with 95 % confidence intervals was estimated for any disability and each disability functioning domain in adolescents (ages 12–17) and young adults (ages 18–25) from PACE Vermont and compared with national estimates with 95 % confidence intervals from the 2021 NHIS and NSDUH. Prevalence of disability from PACE Vermont by category from the single-item question was compared to disability category estimates from 2020 NSHD. Responses to the WG-SS were estimated from those who answered “yes” to the single-item disability question using PACE Vermont and NSHD. Responses to the single-item disability question were also estimated among those who endorsed one of the six-item WG-SS questions using PACE Vermont. A crosstabulation of the WG-SS and the

single-item disability question from PACE respondents are presented alongside positive percent agreement, negative percent agreement, and overall agreement for disability domains (Han et al., 2022) for WG-SS questions that had a corresponding category in the follow-up question from the single-item question (i.e., any, cognitive, mobility).

Given the prevalence of the mental illness/psychiatric disability domain from the single-item measure in both PACE and the NSHD sample, we also explored the correlation between mental health and disability using the WG-SS disability question set. We estimated the prevalence of anxiety and depressive symptoms among those AYAs who did and did not endorse disability.

3. Results

[Table 1](#) displays the prevalence of disability by age group in PACE Vermont, NHIS, and NSDUH using the WG-SS. In the PACE Vermont sample, the overall prevalence of AYAs with disabilities was 20.4 % (95 % CI 14.7, 27.5) using the WG-SS and 10.6 % (95 % CI 6.1, 17.6) using the single-item disability question. When comparing across datasets, the prevalence of any disability in adolescents ranged from 17.0 % (95 % CI 8.5, 30.8; PACE Vermont) to 17.9 % (95 % CI 16.6, 19.3; NSDUH) and in young adults from 3.9 % (95 % CI 3.1, 5.0; NHIS) to 22.0 % (95 % CI 10.2, 24.7; PACE; [Table 1](#)). Cognitive was the most prevalent disability domain endorsed across age groups and samples. There was a higher prevalence of any disability in females (vs. males) and those identifying as non-Hispanic white (vs. other race/ethnicity) in all three samples ([Table S3](#)).

[Table 2](#) displays the prevalence of each disability category endorsed by AYAs using the single-item measure in PACE Vermont and the NSHD. In PACE Vermont, the prevalence of disability was 6.9 % (95 % CI 2.8, 15.9) in adolescent and 18.5 % (95 % CI 2.2, 69.4) in young adults using the single-item disability question. Mental illness/psychiatric disability was the most prevalent disability category for adolescents (81.5 %; 95 % CI 30.6, 97.8 %) while chronic illness or disease was the most prevalent for young adults (36.7 %; 95 % CI 11.8, 71.5 %). Mental illness/psychiatric disability (44.0 %; 95 % CI 32.3, 56.4 %) was the most prevalent disability among young adults in the NSHD, while mobility disability (12.3 %; 95 % CI 6.4, 22.4) was the second most prevalent disability among young adults in this survey.

[Table 3](#) displays the overall, positive, and negative percent agreement between the WG-SS and single-item question in PACE participants, when possible. Overall positive percent agreement between the WG-SS and single-item question in PACE participants was low: 46 % for any disability, 2 % for cognitive disability, and 43 % for mobility disability. Furthermore, of PACE participants who responded “yes” to the WG-SS, less than a third also endorsed the single-item disability question (adolescents: 31.2 %; 95 % CI 10.4, 63.9; young adults: 21.7 %; 95 % CI 10.0, 40.7; [Table S4](#)). NSHD uses the single-item question as a screener question, so all participants endorsed this question to be included in the sample. Of NSHD participants, 62.3 % (95 % CI 49.7, 73.4) endorsed a WG-SS question, indicating they endorsed both the WG-SS and the single-item ([Table S5](#)).

Across surveys, a higher percentage of combined AYAs with any disability as identified by the WG-SS reported anxiety and depressive symptoms as compared to those who did not report a disability (PACE anxiety: 79.0 % vs 19.7 %; PACE depressive: 51.6 % vs 9.0 %; NSDUH depressive: 47.3 % vs 14.3 %; NHIS anxiety: 37.4 % vs 3.9 %). [Table S6](#) displays the prevalence of AYAs endorsing anxiety or depressive symptoms by WG-SS disability status.

4. Discussion

The prevalence of disability among AYA in Vermont varied based on the measures used. When using the WG-SS, the prevalence of any disability was 17.0 % in adolescents and 22.0 % in young adults, which for young adults is higher than NHIS (3.9 %) and NSDUH (12.9 %)

Table 1

Prevalence of disability and disability domain using the Washington Group-Short Set by age group. Data are from the 2021 Policy and Communication Evaluation Vermont, 2021 National Survey on Drug Use and Health, and 2021 National Health Interview Survey.

Characteristic	Adolescents (12–17)				Young adults (18–25)					
	2021 PACE Vermont (n = 144)		2021 NSDUH (n = 10,743)		2021 PACE Vermont (n = 364)		2021 NSDUH (n = 13,979)		2021 NHIS (n = 2,218)	
	n	% ^a (95 % CI)	n	% ^a (95 % CI)	n	% ^a (95 % CI)	n	% ^a (95 % CI)	n	% ^a (95 % CI)
Disability Status										
No Disability	112	83.1 (69.2, 91.5)	8,725	82.1 (80.7, 83.4)	266	78.0 (69.0, 85.0)	11,736	87.8 (86.8, 88.7)	2,129	96.1 (95.0, 96.9)
Any Disability ^a	32	17.0 (8.5, 30.8)	1,907	17.9 (16.6, 19.3)	98	22.0 (15.0, 30.1)	1,664	12.2 (11.3, 13.3)	89	3.9 (3.1, 5.0)
Disability Domain										
Cognition	27	15.6 (7.5, 29.6)	1,423	13.5 (12.3, 14.8)	69	16.2 (10.2, 24.7)	1,003	7.5 (6.8, 8.3)	62	2.8 (2.1, 3.7)
Communication	4	2.4 (0.5, 10.2)	418	3.8 (3.2, 4.4)	12	3.8 (1.6, 8.9)	286	2.0 (1.6, 2.5)	21	1.0 (0.7, 1.6)
Hearing	0	0 (0, 0)	117	1.0 (0.8, 1.3)	6	2.9 (0.1, 8.3)	156	1.1 (0.8, 1.4)	4	0.1 (0.0, 0.4)
Mobility	2	2.1 (0.4, 9.7)	88	0.6 (0.5, 0.9)	8	0.9 (0.2, 3.5)	121	0.7 (0.5, 1.0)	10	0.5 (0.2, 0.9)
Self-Care	3	1.5 (0.2, 10.8)	330	3.2 (2.7, 3.9)	17	5.2 (2.2, 11.9)	279	2.2 (1.9, 2.5)	12	0.5 (0.3, 0.9)
Vision	1	0 (0, 0)	280	2.4 (2.0, 2.9)	21	3.7 (1.8, 7.6)	443	3.1 (2.6, 3.7)	13	0.6 (0.3, 1.1)

Note: PACE = Policy and Communication Evaluation Vermont; NSDUH = National Survey on Drug Use and Health; NHIS = National Health Interview Survey.

^a Respondents who indicated either “a lot of difficulty” or “cannot do at all” to any of the Washington Group Short Set (WG-SS) six-item set of questions to measure disability.

Table 2

Prevalence of disability category endorsed by adolescent and young adults using the single-item measure. Data are from the 2021 Policy and Communication Evaluation Vermont and 2020 National Survey on Health and Disability.

Characteristic	PACE Vermont (2021)				NSHD (2020)	
	12–17 (n = 137)		18–25 (n = 351)		18–25 (n = 205)	
	n	% (95 % CI)	n	% (95 % CI)	n	% (95 % CI)
Single-item question						
Do you have a physical or mental condition, impairment, or disability that affects your daily activities OR that requires you to use special equipment or devices, such as a wheelchair, walker, TDD [telecommunications device for the deaf] or communication device?						
No	126	93.1 (84.1, 97.2)	306	81.5 (30.6, 97.8)	0	(0 %)
Yes	11	6.9 (2.8, 15.9)	45	18.5 (2.2, 69.4)	205	(100 %)
Category						
Intellectual/cognitive	1	0 (0, 0)	4	24.5 (3.1, 76.8)	13	8.4 (3.6, 18.4)
Mental illness/psychiatric	7	81.5 (30.6, 97.8)	17	33.1 (10.9, 66.8)	80	44.0 (32.3, 56.4)
Chronic illness or disease	3	18.5 (2.2, 69.4)	15	36.7 (11.8, 71.5)	40	11.0 (5.4, 21.2)
Physical/Mobility disability	0	0 (0, 0)	5	5.7 (1.0, 26.1)	30	12.3 (6.4, 22.4)
Sensory	0	0 (0, 0)	0	0 (0, 0)	10	6.5 (2.7, 15.0)
Developmental	0	0 (0, 0)	1	0 (0, 0)	17	7.9 (3.5, 16.6)
Neurological	0	0 (0, 0)	3	0 (0, 0)	15	10.0 (4.6, 20.3)

Note: PACE = Policy and Communication Evaluation Vermont; NSHD = National Survey on Health and Disability.

national estimates but consistent with prior estimates of AYA with disabilities (Cheng and Shaewitz, 2020; Trends in prevalence of disabilities among youth, 2022; Senders et al., 2022; Schulz et al., 2023). The PACE young adult estimate approximates the 2021 prevalence of disability in

those aged 18–44 from BRFSS (21.2 %) (Centers for Disease Control and Prevention, 2024); but PACE estimates are greater than the prevalence of disability in those aged 5–17 (6.0 %) and aged 18–34 (7.6 %) from the U.S. Census Bureau (U.S. Census Bureau, 2021); both of which use the ACS 6-item question set. Estimates from the surveys did vary greatly in young adults, from 3.9 % in NHIS to 22.0 % in PACE. The wide range of prevalence estimates could reflect differing ways the questions were administered in surveys, sample variability due to small sample sizes, or true differences in disability prevalence in the population sampled and further highlight the need for future research in disability surveillance. Similar to a prior state estimate (Senders et al., 2022); cognitive limitations were the most prevalent in both age groups. The single item question on disability captured fewer than a third of those who endorsed the WG-SS, while the WG-SS captured approximately 70 % of those who endorsed the single-item question on disability. Percent agreement between these measures was low.

The reason for low positive agreement between a single-item question on disability and the various WG-SS questions is unclear, but several possible explanations exist. First, the single-item question has multiple question parts to which a respondent must attend and therefore may not be fully understood in AYAs, nor has it been used or tested in adolescents. Thus, the single-item may not fully identify people with functional limitations in cognition or communication because of its wording. In fact, approximately 15 % of young adults in the PACE study responded “I don’t know” to the single-item question. On the other hand, both the WG-SS and ACS substantially undercount those with mental health conditions (Hall et al., 2022); with the WG-SS capturing only about 50 % of people with psychosocial disabilities (Washington Group on Disability Statistics, 2020). Additionally, in line with the social model of disability (World Health Organization, 2001); designers of some questionnaires have moved away from the use of the word “disability” (Miller et al., 2011); while the single-item question specifically uses the word “disability.” Conversely, however, a recent survey study found that 39.2 % of respondents who answered “yes” to the question, “Do you have a disability?” did not answer “yes” to any of the ACS functional disability questions, indicating that a substantial portion of individuals identifying as having a disability are not captured by functional questions, and affirming previous findings from the NSHD (Hall et al., 2022; Salinger et al., 2023).

Adolescence is a period during which individuals can begin to develop a disability identity and a sense of disability pride, both of which help to offset societal stigma associated with disability (Forber-Pratt et al., 2021; Andrews et al., 2019; Bogart et al., 2018). Indeed, Andrews and colleagues specifically call upon professionals to more

Table 3

Agreement between the Washington Group-Short Set and single-item disability question. Data are from the 2021 Policy and Communication Evaluation Vermont.

WG-SS disability measures	Single Item		Total n (%)	Overall percent agreement ^a	Positive percent agreement ^b	Negative percent agreement ^c
	Yes n (%)	No n (%)				
Any disability				81	46	88
Yes	40 (8.2)	77 (15.8)	117 (24.0)			
No	16 (3.3)	355 (72.8)	371 (76.0)			
Total	56 (11.5)	432 (88.5)	488 (100)			
Cognitive				82	2	90
Yes	1 (0.2)	86 (17.7)	87 (17.9)			
No	4 (0.8)	396 (81.3)	400 (82.1)			
Total	5 (1.0)	482 (99.0)	487 (100)			
Mobility				98	43	99
Yes	3 (0.6)	6 (1.2)	9 (1.9)			
No	2 (0.4)	476 (97.7)	478 (98.2)			
Total	5 (1.0)	482 (99.0)	487 (100)			

Note: WG-SS = Washington Group-Short Set. Communication, hearing, self-care, and vision did not have a corresponding category in the single-item question and thus, percent agreement could not be calculated.

^a Overall percent agreement was calculated using the following formula: $(a + d)/(a + b + c + d)$.

^b Positive percent agreement was calculated using the following formula: $(2a)/(2a + b + c)$.

^c Negative percent agreement was calculated using the following formula: $(2d)/(2d + b + c)$.

widely use the word “disability” to increase its acceptance and normalcy (Andrews et al., 2019). Notably, more young adults endorsed the single disability item compared to adolescents, perhaps due in part to the fact that young adults are moving away from families and to situations that prompt disability disclosure to access accommodations (Bogart et al., 2018; Chambless et al., 2019). Future research should include qualitative methods to understand how adolescents view their disability or functioning, investigate the impact of health literacy in this context, and explore how adolescents may respond to differing questions and word choice on disability, especially as the Disability Pride movement in the US grows (Miranda, 2021; Shapiro, 2020).

The percentage of adolescents receiving mental health services and the number of children diagnosed with depression have grown in recent years (Lebrun-Harris et al., 2022; Substance Abuse and Mental Health Services, 2020; 2022 National Healthcare Quality and Disparities Report, 2022; U.S Department of Health and Human Services, 2021); which is reflected in the strong correlation between any disability and anxiety and depressive symptoms in AYA. Although the single-item disability question in the PACE Vermont survey captured fewer people with disabilities, 81.5 % of AYA who endorsed the single-item question in the PACE survey noted the one category that would describe their main disability or health condition was “mental illness/psychiatric.” The most common disability domain selected among young adults in the NSHD was also “mental illness/psychiatric.” Adolescents with a range of functioning difficulties (e.g., walking, remembering) have a higher odds of experiencing anxiety and depression symptoms (de Castro et al., 2023) and adolescents with intellectual disabilities have a higher prevalence of psychiatric symptoms (Buckley et al., 2020). Previous research has highlighted the limitation of the WG-SS in identifying people with psychosocial disabilities (Washington Group on Disability Statistics, 2020). The Washington Group has an extended set of questions to identify people who experience disability due to a broader definition of functioning limitations, including those caused by anxiety or depression, but those questions are rarely included in national surveys.

There are several strengths of this study, including measuring disability with two disability identification tools in an understudied population (i.e., AYA). The study also compared estimates with three national surveys using these measures to assess generalizability of findings. Prevalence findings were similar for adolescents; however, prevalence estimates varied for young adults, highlighting the need for

more research in this area. Limitations include the cross-sectional and self-reported nature of the data which were collected during the COVID-19 pandemic; this was likely to have the greatest influence on mental health measures. Additionally, the PACE Vermont Study is a convenience sample from a single, majority rural state. Next, sample sizes are small, especially for disability categories from the single-item question, and therefore findings should be interpreted with caution. Finally, it is unknown whether survey methods, like the use of computer-assisted and in-person data collection methods in NHIS and NSDUH, were sufficient to ensure the accessibility of all surveys and inclusion of all people.

People with disabilities were designated as a population with health disparities by the National Institutes of Health in 2023 (National Institutes of Health, 2023) and make up approximately 25 % of both the adult and the AYA population, yet are largely excluded from clinical research (DeCormier et al., 2022). A necessary first step to reducing health disparities is accurately identifying where they exist. Current disability measures may have a number of limitations; however, it is imperative that researchers and practitioners include questions about disability in their demographic questionnaires, including when conducting research with and providing health services to AYA. Although the measurement of disability is continuously evolving, an immediate starting point for public health researchers and practitioners is to include questions about disability in surveys. Shorter surveys produce higher response and completion rates (Kost and Correa Da Rosa, 2018); however, this study indicates the single-item question may not be comprehensive enough to capture the broad range of functioning domains necessary to ensure health programming is inclusive of all needs and reaches all populations. Rather, the current study supports prior recommendations to add questions to sufficiently capture people with a range of disabilities, especially those with mental and chronic illness (Hall et al., 2022). Alternative disability questions that include mental health and chronic illness, such as those being used in Canada and Australia (Fortune et al., 2023; Statistics Canada, 2020), as well as those that directly ask about having a disability in line with the disability identity movement and similar to other demographic questions (e.g., race, ethnicity, sex), can also be explored. A variety of disability questions should also be compared to the ACS questions, as this is currently the minimum standard for disability questions in the United States. Future studies should assess the validity and reliability of alternative or additional measures to better capture different disability domains and ensure accurate monitoring of health outcomes among people with

disability. Further, it is essential to include people with disabilities in decision-making, especially in consideration of recent proposed changes to the ACS 6-item set on disability questions by the US Census Bureau that were heavily protested by people with disabilities and ultimately not implemented (Wang, 2024; Santos, 2024; National Archives, 2023).

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CRedit authorship contribution statement

Jonathan A. Schulz: Writing – original draft, Visualization, Methodology, Formal analysis, Conceptualization. **Jean P. Hall:** Writing – review & editing, Investigation. **Julia C. West:** Writing – review & editing, Investigation. **Allison M. Glasser:** Writing – review & editing, Investigation. **Dana E. Bourne:** Writing – review & editing. **Cristine D. Delnevo:** Writing – review & editing. **Andrea C. Villanti:** Writing – review & editing, Validation, Methodology, Conceptualization.

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Data availability

Data will be made available on request.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pmedr.2024.102770>.

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